Consolidated Health Informatics

Standards Adoption Recommendation

Disability

Index

Summary

Domain: Disability

Standards Adoption Recommendation:

No standard is being recommended to be adopted at this time for disability content needed by the Federal Government. However, recommendations are offered to guide research that will facilitate the development of the of (i) needed disability and functional content into core terminologies, and (ii) algorithms that can be used to equate the alternative scaling concepts used across federal classification systems.

RECOMMENDATION
There is no standard being recommended at this time. However, recommendations are included to guide future work in the area of disability content and questions.

OWNERSHIP
-NA-

APPROVALS AND ACCREDITATIONS
-NA-

ACQUISITION AND COST
-NA-

Part I – Team & Domain Scope Identification

Target Vocabulary Domain

Common name used to describe the clinical/medical domain or messaging standard requirement that has been examined. Disability

Describe the specific purpose/primary use of this standard in the federal health care sector (100 words or less) This standard would be used to describe disability terms that are used in the federal health care sector. Examples are: ♦1 Use by Medicare/Medicaid, VHA, SSA and CDC. ♦2 Use for payment, surveys, public quality reports, external quality monitoring, internal quality monitoring, eligibility determinations and policy development.

Sub-domains Identify*/dissect the domain into sub-domains, if any. For each, indicate if standards recommendations are or are not included in the scope of this recommendation.*

Domain/Sub-domain	In-Scope (Y/N)
IRF PAI for Medicare inpatient rehabilitation hospitals / units (embeds all but one FIM item).	Y
OASIS for Medicare home health	Y
MDS for Medicare/Medicaid skilled nursing facilities	Y
FIM is used in all VA Hospitals for specific impairment groups (Stroke, Lower Extremity amputation and Brain injury).	Y
RFC is used for eligibility, to assist in claims processing, to define policy for advocacy, to standardize terminology for rule making and for training of new non-medical personnel.	Y
(CDC) National Health Interview Survey, National Health and Nutrition Examination Survey	Y

Information Exchange Requirements (IERs) *Using the table at appendix A, list the IERs involved when using this vocabulary.*

IERs
Body Inquiry Information
Body of Health Services Knowledge
Care Management
Case Management
Clinical Guidelines
Cost Accounting Information
Customer Approved Care Plan
Customer Health Care Information
Customer Risk Factors
Population Member Health Data
Population Risk Reduction Plan
Referral Information
Tailored Education Materials

Team Members *Team members' names and agency.*

Name	Agency/Department
Jennie Harvell (Co-Chair)	HHS / ASPE
Samuel Shipley (Co-Chair)	HHS / ASPE
Vivian Auld	HHS / NIH / NLM
Laurence Desi Sr., MD, M.P.H.	SSA
Derek Wang	SSA
Marjorie Greenberg	HHS / CDC
Paul Placek, Ph.D.	HHS / CDC
Bill Wenninger, MS. PT	VA
Jean Scott, Dr. P.H., RN	HHS / CMS
Nancy Orvis	DoD
Susan Levy-Bogasky	HHS/ASPE

Work Period *Dates work began/ended.*

Start	End
July 2003	April 2004

Part II – Standards Adoption Recommendation

Recommendation *Identify the solution recommended*

There is no standard being recommended at this time. However, recommendations are included to guide future work in the area of disability content and questions.

Ownership Structure *Describe who "owns" the standard, how it is managed and controlled.*

Not Applicable

Summary Basis for Recommendation *Summarize the team's basis for making the recommendation (300 words or less).*

At this time, the workgroup does not recommend adoption of any of the standards that were evaluated. However, the workgroup offers the following recommendations to guide future work in this area:

1. Regarding disability content:

- 1 Future study in disability content should further examine whether and how the underlying hierarchies of SNOMED CT® need to be modified to support the incorporation of needed disability terms, concepts, and phrases.

- 2 The disability community and terminology community need to work together to enhance and further develop existing granular terminology for the disability domain to support the needs of the federal government, including needed scaling concepts embedded in federal classification systems and assessment instruments.

- 3 This work can be facilitated by a full mapping between SNOMED CT® and ICF® and examination of other sources in the UMLS®.

2. Public and private sectors undertake the following activities with respect to disability questions:

- 1 Future research and policy development efforts should consider whether LOINC® contains needed disability questions.

- 2 Work with LOINC® to enhance coverage of disability questions used by the Federal government.

Conditional Recommendation *If this is a conditional recommendation, describe conditions upon which the recommendation is predicated.*

Not Applicable

Options Considered Inventory *solution options considered.*

SNOMED CT® (Systematized Nomenclature of Medicine - Clinical Terms)
ICF® (International Classification of Functioning, Disability and Health)
Other Sources in the UMLS® (Unified Medical Language System) Metathesaurus®

Detailed Report of Background, Findings and Conclusions

Background

Given the increasing interest in electronic health records as a key cornerstone to the National Health Information Infrastructure, the CHI Disability Workgroup was asked to consider whether available clinical terminologies and/or vocabularies should be recommended as a vocabulary standard for future federal health related systems that use disability concepts. Disability terms are used in the federal health care sector in many ways, including:

1 CMS uses disability terms for payment, quality assurance and/or public reporting of quality indicator in home health, nursing homes, and rehabilitation hospitals/unit providers.
2 CDC/NCHS uses disability terms in their surveys for monitoring the health and functioning of the population and the factors that influence population health and functioning. These national surveys are used to guide policy development.
2 SSA uses disability terms from the Residual Functional Capacity forms (RFC) for eligibility, to assist in claims processing, to create policy, to standardize terminology and for training of new personnel.
3 VA uses disability terms in eligibility determinations and in internal quality monitoring for all persons with certain disabilities across the continuum of care and for all individuals who are admitted to a formal acute or sub-acute rehabilitation program.

Potential alternatives considered were:

1 SNOMED CT® because: (i) it is generally regarded by medical informatics professionals as the largest and most leading clinical terminology database with more than 352,000 concepts, 939,000 synonyms, and 1,360,000 relationships
2 ICF® in its scope because it is the only internationally recognized classification and coding set regarding functional status.
3 UMLS Metathesaurus® for disability terms needed by the Federal Government might identify other vocabularies that should be considered.

Appendix A contains a description of these alternatives.

Methods

The Workgroup decided to approach a content coverage analysis of SNOMED CT®, ICF®, and the UMLS Metathesaurus® by sampling disability terms/concepts used across participating federal agencies. We sampled terms used in Medicare and Medicaid

programs, Social Security Administration, Veterans' Health Administration, and surveys conducted by the National Center for Health Statistics (NCHS). In sampling terms, the Workgroup identified disability terms/phrases/content that were applicable to physical and mental disability, children and adults, and are used by the Federal Government to meet a variety of purposes (e.g., payment, quality, eligibility, research, statistics, and policy development). Specifically, disability terms and concepts were sampled from the:

1. Nursing Home Minimum Data Set (MDS);
2. Home Health Outcome and Assessment Information Set (OASIS); and
3. Functional Independence Measure (FIM) for Rehabilitation;
4. Residual Functional Capacity Form (RFC); and
5. National Health Interview Survey and National Health and Nutrition Examination Survey.

Items one through four are patient assessment tools, at least 3 of which are enumerated, predefined coding schemes used by the Federal Government. The fifth item reflects a variety of survey instruments developed and/or implemented/sponsored by the Federal Government.
Appendix 2 contains a description of items 1-5.

Each of the coding schemes and surveys captures information related to disability. However, the disability information captured by each code set/survey differs in terms of the domains of disability that are measured, how disability is assessed, and how levels of disability are scaled. Even when similar levels of disability seem to be measured across code sets/surveys (e.g., bathing), differences exist in how tasks are defined, and how disability is assessed and scaled.

Each workgroup representative created a sample of disability concepts and phrases used by their agency and provided these on spreadsheets. Rows contained the sampled terms and columns were used to record complete, partial, or no matches found in the alternatives.
Appendix 3 contains copies of the original spreadsheets.

A workgroup member from the National Library of Medicine, s. Vivian Auld, analyzed the concepts and phrases recorded on each spreadsheet. In completing the content coverage analysis, Ms. Auld used the MetaMap Transfer (MMTx) Program, developed by the National Library of Medicine, a highly configurable program that maps biomedical text to concepts in the UMLS Metathesaurus®. MetaMap works by parsing text into simple noun phrases, identifying variants (acronyms, abbreviations, synonyms, etc.), listing candidate strings within the UMLS Metathesaurus® that contain at least one of the variants, and finally identifying the most likely concept match within the UMLS Metathesaurus®.

Ms. Auld planned to run the terms, phrases, and concepts included in the spreadsheets submitted by the Disability Workgroup team members against MetaMap, then run the resulting list of noun phrases against the Clue Browser (SNOMED CT®) and the ICF®

Browser. However, Ms. Auld encountered difficulties in using MetaMap and instead had to identify matches by hand rather than by machine. Ms. Auld's analysis identified the most likely concept matches within the UMLS Metathesaurus® for the RFC, MDS, OASIS and the FIM (see **Appendix 4** for this analysis).

The workgroup then determined that, because the UMLS Metathesaurus® is a compilation of a number of vocabulary databases, the Workgroup would focus its attention on evaluating SNOMED CT® and the ICF®, the two leading candidates for this domain. Ms. Auld then completed the content coverage analysis of SNOMED CT® and ICF® for the RFC, OASIS, and the FIM. See **Appendix 5** for these spreadsheets.

However, because of the limited time remaining, the Disability Workgroup reduced the number of sampled MDS and NCHS items that would be included in the SNOMED CT® and ICF® content coverage analyses. In addition, because of time constraints, the Workgroup limited its review of the OASIS content coverage analysis to a sub-sample of disability terms/concepts. See **Appendix 6** for the streamlined MDS, OASIS, and NCHS spreadsheets.

The workgroup then reviewed the output from Ms. Auld's work. The Workgroup's review of Ms. Auld's work incorporated:

1 The expertise of Workgroup members familiar with each of the federal disability use cases;
2 A review of the ICF® codes recommended by Ms. Auld as providing coverage for the identified federal disability term/concept/phrase (including a limited review of ICF® when Ms. Auld found that ICF® did not provide coverage of an identified term/concept/phrase), and
3 A review of Ms. Auld's designation of SNOMED CT® and ICF® as providing full/partial/no match for identified terms/concepts/phrases.

<u>Major Analytic Limitation</u> It is important to note two significant limitations of the Workgroup's findings:

1. The Workgroup did <u>not</u> validate the accuracy of Ms. Auld's findings that SNOMED CT® provided some level of coverage or failed to provide coverage for federal disability terms/concepts/phrases. This is in contrast to our review of ICF® coverage in which the Workgroup, independent of Ms. Auld, reviewed the availability of ICF® coverage. The Workgroup was able to complete such an independent assessment of the ICF® by reviewing the codes and definitions in the ICF® manual. As a result of this review, there were instance in which the Workgroup disagreed with some of Ms. Auld's findings that in some cases the ICF® provided coverage and in other instances failed to provide coverage for identified federal terms.

2. The Workgroup reviewed the level of matching for both SNOMED CT® and ICF® as reported by Ms. Auld.

For the ICF® review, the Workgroup used: (i) its expertise in understanding the federal data needs; (ii) to the extent time permitted, the ICF® manual to validate the reported match; and (iii) contrasted its expert opinion and awareness of the ICF® content with the terms Ms. Auld included on the spreadsheets.

In reviewing the matching levels reported for SNOMED CT® the Workgroup relied on (i) its expertise in understanding the federal data needs; and (iii) contrasted its expert opinion with the terms Ms. Auld included on the spreadsheets.

The implications of the Workgroup not independently validating (i.e., independently reviewing) the SNOMED CT® content and matching levels for sampled federal disability terms/concepts/phrases is that the Workgroups' findings with respect to SNOMED CT® (i) coverage and (ii) matching levels could in some instance overstate the level of coverage and in other instances understate the level of coverage provided by SNOMED CT®.

Findings

1. Based on an extensive review of the completed SSA spreadsheet, the Workgroup reached the following general conclusions:

> ***Based on a review of the SNOMED CT® and ICF® coverage of sampled SSA scaling items, the Workgroup concluded that neither SNOMED CT® nor ICF® would adequately addresses the disability scaling needs of the involved federal agencies.***

SSA scaling items included (but were not limited to) items such as:

- Not significantly limited, moderately limited, and markedly limited
- Frequently, occasionally, never
- No limitation, less than marked limitation, marked limitation, and extreme limitation

At best, the Workgroup found that SNOMED CT® and ICF® provided a partial match of these concepts because:

At a minimum, and in all cases, both SNOMED CT® and ICF® would require the development of algorithms to translate the scaling embedded in the terminology/classification scheme to support the scaling needs of (i.e., the metric needed by) SSA. Neither ICF® nor SNOMED CT® includes the scaling concepts needed by SSA. The Workgroup concluded that this would be the same result for SNOMED CT® and ICF® coverage of the scaling embedded in the FIM, OASIS, and MDS.

Some times the scaling content was either unavailable or only partially available.

Additional Limitation of Analysis: The Workgroup limited our scaling analysis to the semantic coverage provided by ICF® and did not consider whether the percentages provided by ICF® of the magnitude of impairment were equivalent to or could be reconciled with the scaling levels established by the SSA.

Based on the preceding analysis the Disability Workgroup excluded from further content coverage analyses any scaling items embedded in federal disability data items (note: in the streamlined NCHS spreadsheet the concept of "difficulty" was retained for several items).

2. Based on its review, the Workgroup reclassified many of the sampled federal disability terms, concepts and phrases in terms of whether SNOMED CT® and/or ICF® provided a complete, partial or no match. **Appendix 7** contains the spreadsheets of final sampled terms, the Workgroup's determinations of complete, partial and no matches, and a tally of the coverage provided by SNOMED CT® and ICF®.

> ***Briefly, based on a review of the SNOMED CT® and ICF® coverage of and levels of match rates for disability terms/concepts/phrases sampled from the MDS, OASIS, RFC, FIM, and NCHS survey questions (excluding all previously sampled scaling items), the Disability Workgroup concluded that neither SNOMED CT® nor ICF® would adequately addresses the disability data needs of the involved federal agencies. Both SNOMED CT® and ICF® (i) failed to include many specific disability terms/concepts/phrases needed by the Federal Government; and (ii) often when coverage was available, only partial coverage of a federal term/phrase/concept would be found in either SNOMED CT® or ICF®.***

It should be noted that when reviewing the NCHS spreadsheet the Workgroup excluded from its review the concept of "difficulty." Specifically, the Workgroup excluded the term "difficulty" (e.g., difficulty: seeing, understanding other people when they talk, managing medications, etc.). The concept of difficulty is captured in the ICF® as a "qualifier" (i.e., items that the workgroup considered to be scaling items). However, the ICF® qualifiers do not always align as an exact match with the items sampled from the surveys. Had the Workgroup considered the concept of "difficulty" the ICF® would have been found to provide partial coverage for these sampled survey items.

NCHS advised the Workgroup that some of parenthetical terms in the sampled questions on the environment were examples or clarifications to those questions and should not have been included in the content coverage analysis. Thus, for example, in the case of "Building design (stairs, bathrooms, narrow or heavy doors)," the terms in the parentheses were not included in the Workgroup review. By excluding the parenthetical terms, the match for the ICF® was found to be complete rather than partial.

The table below summarizes the results of the CHI Disability Workgroup content coverage analysis.

Content Coverage Table							
			SNOMED CT®			**ICF®**	
		Complete	Partial	None	Complete	Partial	None
FIM (n=100)	Quality	58	40	2	30	64	6
	Total	**58**	**40**	**2**	**30**	**64**	**6**
(n=97)	Payment	56	39	2	30	61	6
	Total	**56**	**39**	**2**	**30**	**61**	**6**
OASIS (n=39)	Payment	7	1	1	1	6	2
	Quality	8	13	9	6	9	15
	Total	**15**	**14**	**10**	**7**	**15**	**17**
MDS (n=31)	Payment	10	16	0	3	17	6
	Quality Indicators	8	3	0	3	5	3
	Quality Measures	8	3	0	3	5	3
	Care Planning	8	3	0	3	5	3
	Total	**14**	**17**	**0**	**4**	**21**	**6**
RFC (n=81)	Eligibility Adults	41	8	2	39	11	1
	Eligibility Children	17	13	0	25	5	0
	Total	**58**	**21**	**2**	**64**	**16**	**1**
NCHS (n=70)	**Survey**	32	34	4	12	40	18
	Total	**32**	**34**	**4**	**12**	**40**	**18**
Grand Total (n=418)		**233**	**165**	**20**	**147**	**217**	**54**

(*) Columns don't necessarily add up because items are used for multiple purposes.

Additional Information Gathering

The Disability workgroup had a fact-finding conversation with CAP on the subject of SNOMED CT® and Disability content and hierarchies. CAP believes that SNOMED CT® supports disability content and indicated that they will need advice about needed Disability hierarchies. CAP has been asked by Denmark, Netherlands, and Wales to map the ICF® to SNOMED CT® (they reported that these countries are using the ICF®). CAP indicated that these countries want the ICF® mapped to SNOMED CT® as a solution to their EHRs. Reportedly these countries are using SNOMED CT® in their acute care settings and until ICF® is mapped to SNOMED CT® they lack the content

needed for admissions, transfers, and discharges.

In reviewing the ICF®, OASIS, FIM, and MDS items included in the earlier email message to CAP, CAP reported that many of the terms in that email message are included in SNOMED CT®. However, CAP observed that some of the MDS and FIM terms are "very pre-coordinated" and that their inclination is to ensure the inclusion of needed terms (rather that an unending list of pre-coordinated concepts). This strategy would allow whatever post-coordination of concepts would be needed.

NCVHS Presentation: December 10, 2003

NCVHS is a Federal Advisory Committee to the Secretary of Health and Human Services. Therefore, all of its proceedings are public and can be obtained on the ncvhs.hhs.gov website. However, for the purposes of condensing the discussion, a summary is provided here.

As with all CHI workgroup recommendations, the Disability Domain Workgroup presented its report to the NCVHS Standards and Security Subcommittee. NCVHS suggested that the recommendation to "develop algorithms that can be used to equate alternative scaling concepts across federal classification systems" went beyond the scope of the CHI (i.e., Disability Workgroup recommendation item 2d).

NCVHS recommended that we consider adding as needed next steps to research the following:

a. Explore the structure needed for sharing data (i.e., what message formats and content are needed) to unambiguously communicate information.

b. Consider the implications of the information needs of public health/regulatory agencies and that which is needed in the course of care giving. Also consider different information needs/requirements by different disability areas (e.g., persons who are blind vs. deaf, etc.).

NCVHS commented that SNOMED CT® might be able to cover part of the information needs required by public health/regulatory programs but not for patient care.

c. Given that much of the federal disability data emerges as a result of survey-like instruments, explore whether different vocabularies could be used for questions and answers. Specifically, consider the utility of LOINC® (or something like LOINC®) for questions and SNOMED CT® for the answers.

   With respect to LOINC®, the Committee observed that it is bi-directional and usually provides the questions. For example, it may be able to address, "What is the reason for Disability?" The answer to the question

may have to come from clinical terminology such as SNOMED CT®.

A general comment made by NCVHS was that some believe that it will be necessary to first standardize the questions across use cases and then identify the vocabulary/terminology.

NCVHS recommended that the Workgroup consider the NCVHS comments and report back after the research is completed. The Subcommittee felt that the Disability community, in particular those who are involved in reporting, need to develop an informatics based consensus toward the way information will be communicated.

Consultation with LOINC®

The disability workgroup held a conference call with Dr. Clem McDonald of Regenstrief, the developers of the Logical Observation Identifier Names and Codes (hereafter referred to as LOINC®).

LOINC® is a metadata registry of health related questions. These questions are maintained in LOINC® in a standard form that permits categorization and retrieval by different categories. This, in itself, could be a useful exercise for federal disability questions. The information in LOINC® includes the source / developer of each question. However, LOINC® does not include information about the reliability / validity of questions for their intended purpose. A metadata registry of health related questions is a useful source of information to access when specifying health information needed for different purposes. However, the content of LOINC® is limited with respect to disability questions.

<u>Observations</u>

In addition, during its review of coverage provided by SNOMED CT® and the ICF®, the Workgroup made the following observations and raised the following questions:

1. While a finding of a complete match or of no match was fairly absolute, the Workgroup found varying levels of partial coverage. For example:

   The Workgroup concluded that the concept of (i) breaking into a house, building or car; lying to get money or snatching someone's purse or jewelry were partially covered by ICF® and SNOMED CT®. For ICF® the conclusion of a partial match was based on the availability of the concepts of following "social norms, practices, and ideologies" (item e465). For SNOMED CT® the conclusion of a partial match was based on the availability of the concepts of "criminal behavior," "telling untruths," and "theft."

2. As a classification system, the ICF® often bundles multiple concepts. However, in many cases, the Federal Government needs disability data for only a part of the bundled concepts. Thus, a classification system will not always permit the

extraction of data needed by the Federal Government. How the ICF® defines the concept "Emotional Function (b 152)" illustrates this point.

The ICF® manual defines Emotional Function as "Specific mental functions related to the feeling and affective components of the processes of the mind. *Inclusions: functions of appropriateness of emotion, regulation, and range of emotion; affect; sadness, happiness, love, fear, anger, hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect. Exclusions: temperament and personality functions (b126); energy and drive functions (b130)* (italics included).

The OASIS includes several items regarding patients' emotional status including:

- Patients in a "constant disorientation, coma, persistent vegetative state, or delirium" (OASIS item M0560-4);
- Patients "confused …in new or complex situations only… during the day or evening, but not constantly" (OASIS item M0570- 2 and 4);
- Patients "anxious… less often than daily…daily but not constantly" (OASIS item M0580- 1 and 2);
- Patients "depressive feelings…depressed mood… sense of failure…hopelessness… recurrent thoughts of death…thoughts of suicide…" (OASIS item M0590- 1, 2, 3, 4, and 5)

The construction of the ICF® will not permit the separate collection of data presently required in the OASIS instrument and used to create home health payment rates and quality indicators because in this example the ICF® either does not capture the information needed by the Federal Government or bundles concepts that the Federal Government separately measures (e.g., anxiety and sadness). Further, the ICF® classification also captures other affective characteristics that are not needed by the government.

3. The ICF® is intended to be complementary to the International Statistical Classification of Diseases and Related Health Problems (ICD). Thus, as highlighted in the preceding example while the ICF® does not reflect specific medical codes, the ICD does include codes for specific medical conditions that were included in the final CHI Disability Workgroup spreadsheets of sampled terms including: asthma, learning disability, disorientation, confusion, anxiety, and depression.

4. The Workgroup was concerned about whether the multi-axial hierarchies that are the foundation of SNOMED CT® presently support or could be modified in the future to support disability terms and constructs needed by the Federal Government (and by health care providers). This issue was raised in part because of the origins of SNOMED CT® (i.e., a model originally intended to represent diseases and procedures and its continued emphasis on medical content) and also because we found SNOMED CT® providing more complete coverage of medically-related terms compared to the ICF® (e.g., the provision of Nursing, Rehabilitative, Restorative Care such as in the areas of active and passive range of

motion, and training and skills practice in amputation/prosthesis care (MDS item P3 a, b, and i)).

5. Further, even to the extent that all relevant disability and functioning terms were included in SNOMED CT® (or some other terminology) and endorsed for future federal use, additional work would be needed to map to the classification systems used by federal agencies (including, but not limited to, classifications (derived from patient assessment tools) that are used to generate Medicare and Medicaid payments, and the ICF®). The Workgroup notes the terminology itself would also not be sufficient to provide a conceptual framework for understanding functioning and disability (i.e., a strength of the ICF®).

6. The Workgroup is aware of recent research completed by the Mayo Clinic that found, in a review of the domains of pressure ulcer, incontinence, and pain, most of the information collected using the MDS for these domains is not captured by either SNOMED CT® or ICF®. Specifically, SNOMED CT® was found to provide a complete match for 46% of the MDS terms. The ICF® was found to provide a complete match rate of terms in the MDS 2 percent of the time.

Recommendations

In its letter of November 5, 2003 **(see Appendix 8)** the NCVHS recommended that the Federal Government "recognize a "core set" of PMRI [Patient Medical Record Information] Terminologies as a national standard. This core set should comprise the minimal set of terminologies that (1) are required to adequately cover the domain of patient record information and (2) meet essential technical criteria to serve as *reference terminologies*" (italics included). The characteristics of well-formed reference terminology include (source: Mayo Paper, **see http://aspe.hhs.gov/daltcp/reports/toward.pdf**):

1 *Concept orientation*: Provides the tools that empower users to adapt "local terms" to reference terminologies (i.e., accommodates synonymy and lexical variants, and a thesaurus must be available for automated identification of terms associated with concepts);
2 *Comprehensive and complete*: Provides the depth and breadth of content coverage relevant to specific domains;
3 *Atomic and compositional*: Ensures that "atomic" levels of data are available and that the meaning of atomic level data elements is preserved when combined or post-coordinated with other concepts;
4 *Explicit formalism (e.g., description logic)*: Must have a formal logic or inference engine that enables the post-coordination of more complex expressions from atomic level data elements;
5 *Multiple classifications*: Must enable concepts to be mapped to multiple classification systems; and
6 *Representation of context*. Must be coordinated with structural models of clinical

documents within the electronic record in order to disambiguate meaning from use.

In this letter, the NCVHS identifies SNOMED CT® as "the general terminology for the core set of PMRI terminologies." The NCVHS found that based on its breadth, model, and widely recognized value it supports its use for the "exchange, aggregation, and analysis of patient medical information." The NCVHS also acknowledges the license between the College of American Pathologist (the developers of SNOMED CT®) and the NLM makes it freely available for use in the U.S. The NCVHS also recommended other standards as "core standards" and recommended that SNOMED CT® and other core standards be integrated within the UMLS®. The letter from the NCVHS concludes with issues requiring additional research including "exploring the incorporation of content from terminologies other than those selected for the core set of PMRI terminologies." The NCVHS specifically mentions the ICF® as being "a valuable source of concepts for encoding functional status."

1. We recommend regarding disability content:

    a. Future study in disability content should further examine whether and how the underlying hierarchies of SNOMED CT® need to be modified to support the incorporation of needed disability terms, concepts, and phrases;

    b. The disability community and terminology community need to work together to enhance and further develop existing granular terminology for the disability domain to support the needs of the federal government, including needed scaling concepts embedded in federal classification systems and assessment instruments.

    c. This work can be facilitated by a full mapping between SNOMED CT® and ICF® and examination of other sources in the UMLS®.

2. We recommend that public and private sectors undertake the following activities in respect to Disability Questions:

    a. Work with LOINC® to enhance coverage of disability questions used by the Federal government;

    b. Future research and policy development efforts should consider whether LOINC® contains needed disability questions.

Appendices:

Appendix 1: Description of SNOMED CT® and ICF®
Appendix 2: Description of federal classification and a patient assessment forms, and federal surveys from which items were sampled for this study
Appendix 3: Original spreadsheets
Appendix 4: Results of Ms. Auld's analysis of matches within the UMLS Metathesaurus® for the RFC, MDS, OASIS and the FIM
Appendix 5: Results of Ms. Auld's analysis of SNOMED CT® and ICF® for the RFC, OASIS, and the FIM
Appendix 6: Spreadsheets with reduced number of sampled MDS, OASIS, and NCHS items that would be included in the SNOMED CT® and ICF® content coverage analyses
Appendix 7: Final Spreadsheets
Appendix 8: NCVHS 11-5-03 Letter
Appendix 9: ASPE – Mayo Clinic study on standardizing MDS concepts